

NIA COORDINATING UNIT

BURDENS OF CARE FOR ALZHEIMER'S DISEASE

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This unit was established in FY 1989 to coordinate all behavioral and social research on Alzheimer's disease and related disorders (ADRD). It provides an identifiable point of contact for interaction within the NIA as well as with the outside community. Its mission is to summarize research findings and to develop and implement a research agenda on topics such as: studies of the physical and psychological consequences of dementia care; interventions to enhance everyday functioning and reduce family caregiving burdens; and the effects and the costs of different long-term care arrangements.

Progress Report. NIA-sponsored research (over 50 funded research projects in this area) examines the extent, causes and consequences of the heavy burden of caring for people with ADRD. The current *NIA Burdens of Care for Alzheimer's Disease Research Overview* has recently been updated.

Current activities center on two highly visible activities: 1) the *Special Care Unit (SCU)* initiative, a set of ten collaborative projects that examines the nature and effectiveness of care in institutional settings, and 2) *Resources for Enhancing Caregiver Alzheimer's Health (REACH)*, a six site collaborative effort to test the effectiveness of different home and community-based interventions for helping families provide care to loved ones with mild and moderate dementia.

SCU: Analyses from the National Evaluation of Special Care Units (Leon, U01 AG10317) reveal a three fold growth in the number of SCUs in licensed nursing facilities in the past decade. As of 1996, nearly one in four nursing homes had at least one organized dementia care unit, wing or unit or program. While SCU effects are not as great as expected, several of the collaborative studies have documented positive impacts on resident's behavior and social interactions. Recent preliminary analyses from the New York State study (Holmes U01 AG10330) suggest that staff time spent in special care units is more effective in reducing troublesome behaviors than equivalent time spent by nurses aides in non-SCUs. Although higher costs of care are documented in special care units, the centralization of care for the most behaviorally disturbed residents in such units may actually result in net savings when analyzing costs at the facility level. Data from all ten sites have now been transferred to the coordinating center, where under the direction of Douglas Holmes and Jeanne Teresi, meta-analyses will be conducted using common core measures developed for such use.

REACH: Using a common core assessment battery, REACH is examining the effects of psychoeducational support groups, behavioral skills training programs, family-based systems interventions, environmental modifications, and technological computer-based information services in Caucasian, Hispanic, and African-American families in Alabama, California, Florida, Massachusetts, Pennsylvania, and Tennessee. Further descriptions of

REACH interventions, populations, measurements and outcomes of interest can be found in the 1998 Progress Report available on the REACH home page (<http://www.edc.gsph.pitt.edu/reach>). Recruitment has been the major issue over the past year, and most sites are now meeting their recruitment goals. Preliminary outcome data will not be available until 1999. Under the leadership of Richard Schulz at the Coordinating Center, REACH investigators are preparing an Oxford University Press book on *Intervention Approaches to Dementia Caregiving*. Substantial scientific activity in the past year has centered on developing a common metric for understanding the relative influence of different intervention strategies.

Research Advances.

Findings will be highlighted in several additional areas: 1) the nature and impact of dementia care as contrasted to caregiving for other chronic illnesses and disabilities; 2) the costs of dementia care by disease severity and setting; 3) the physiological consequences of dementia care; and 4) the effectiveness of social interventions for reducing caregiving burdens.

Perceived impacts of dementia care. Recent national caregiving survey confirms previous assumptions that dementia care is especially taxing. Drawing on telephone interviews with over 1500 family caregivers, the 1996 National Survey on Family Caregiving in the U.S. estimates that over five million American households provide care for someone with dementia or related symptoms. Secondary data analyses (Schulz, U01 AG13305) of this survey document the ways in which dementia care is different from other types of family caregiving. Dementia caregivers provide over 17 hours of care a week, compared to slightly over 12 hours of care provided by non-dementia caregivers. Additionally dementia caregivers are more likely to report providing constant care. These analyses further showed that caregiving had a greater impact on dementia caregivers in terms of time for other activities, family conflict, caregiving strain, the experience of mental and physical problems, financial hardship, and negative feelings. Greater perceived impacts for dementia caregivers remained, even after controlling for intensity of caregiving involvement and socio-demographic factors which might influence the experience of strain (e.g., gender, race, caregiver's age). These findings suggest the need to tailor programs and services to the unique challenges faced by dementia caregivers.

Costs of dementia care. Previous estimates of the costs of Alzheimer's care have been flawed by small restricted samples, samples limited to community residents, or questionable approaches to establish AD diagnoses and/or measure AD disease severity. Using improved methods, Leon and associates (with partial funding from U01 AG10317) provide more precise costs estimates of AD care and document potential dollar attributable to use of alternative care settings and interventions that can delay the rate of decline in memory and physical functioning. Extrapolating costs from a large multi-state sample of 679 Alzheimer's disease patient/caregiver pairs, these investigators estimate annual per patient costs in 1996 for mild, moderate, and severe patients at \$18,408, \$30,096, and \$36,132, respectively. National annual costs of slightly over 50 billion

dollars were calculated using the new GAO prevalence estimates: \$14.9 billion for mildly impaired and \$36.4 billion for the moderately and severely impaired. Analyses modeling the costs of care suggest that large cost savings could be achieved if more AD residential patients were served in assisted living facilities rather than nursing homes (\$11,028 per annum per patient). Additional cost savings are possible if treatment regimens can reverse or delay AD progression, particularly if they delay residential placement. For example, an intervention that delays placement for six months could lead to a savings of over \$12,000 while a delay of one year would save over \$24,000 per patient. However, interventions that delay institutionalization also carry additional burdens for informal caregivers. Thus, it is important to design and test effective strategies for strengthening family caregiving skills and reducing their burdens.

Physiological impacts of dementia caregiving. Chronic stressors are hypothesized to impact health outcomes by causing physiological changes associated with the development of chronic diseases and/or by increasing health impairing behaviors that can also accelerate disease progression. Recently, researchers have set out to fill gaps in our understanding of psychophysiological responses (e.g., changes in immune function, impairments cardiovascular systems, etc.) to chronic stress, as in caring for a spouse with Alzheimer's. These studies are suggesting that there is not one generic response to caregiving burdens, but that certain caregiver characteristics (being male), caregiving tasks (constant care with no respite) or the presence of co-morbidities (having CHD) make particular caregivers especially biologically vulnerable to the stresses associated with dementia care.

For example, Vitaliano and associates (R01-AG10760; R01-AG11143) examined how metabolic levels consistent with coronary heart disease (CHD) compared between caregiver and non-caregiver spouses with the disease, and between the two groups without the disease at two points in time. As expected, metabolic syndrome levels (MSLs) (i.e., cholesterol/triglycerides, glucose, insulin, blood pressure) were found to be higher for caregivers with CHD than non-caregivers with CHD initially and 15-18 months later. Poorer health habits and fewer uplifts were associated with elevated MSLs in caregivers with CHD. Caregivers and non-caregivers without CHD were also found to have similar metabolic levels suggesting that caregiving itself does not place an individual at risk for CHD unless the individual is predisposed to the vulnerabilities that contribute to metabolic changes.

In a related examination of relationships of gender, psychosocial stress/distress and immunological cellular between spouse caregivers with AD and gender-matched persons whose spouses were healthy, Vitaliano and associates (R01 AG10760) found evidence to suggest that men were more physiologically vulnerable to chronic stress than women. In general, CD4 counts (indicative of changes in immunological functioning and vulnerability to disease) were lower for men than for women. In comparisons of the two groups of men, CD4 counts were lower in men who were caregivers. While women caregivers reported more hassles and depression than either non-caregiving women or men caregivers, CD8 cell counts (which trigger a decrease in production of CD4 cells) were positively associated with hassles in men although not in women. Similarly, hassles

were negatively associated with the CD4/CD8 ratio in men but no relationship was noted in women. Further research is needed to specify how gender roles influence physiological adaptation to stress, and what particular interventions might be most successful in reducing perceived stress (e.g., relaxation training, meditation exercises).

In similar work, Grant (R01 AG15301) is analyzing data collected over a period of 6 years from spousal caregivers of Alzheimer's patients and non-caregiver spouses to determine biological mechanisms that may lead to health problems due to caregiving stress. An initial analysis of vulnerable caregivers (e.g., dementia caregivers who provide almost constant care but who have little respite) suggests that vulnerable caregivers of AD patients have a deficit in circulating CD62L-T Lymphocytes. Chronic stress leads to a decrement in T lymphocyte-mediated immunity, a phenomenon mediated in part by the sympathetic nervous system. The data extend prior findings by suggesting that the immune decrement associated with the chronic stress of caregiving may be due to preferential loss of CD8+CD62L- and CD4+CD62L-T lymphocytes. Additional studies are underway to examine the effectiveness of at-home respite care on reducing sympathoadrenalmedullary activation (SAM) in vulnerable caregivers.

Effects of caregiving interventions. Prior research has demonstrated that family caregiving can disrupt social relationships. Social interventions can be beneficial in reducing Alzheimer's caregiving burdens but targeting helps increase their cost effectiveness. Pillmer and colleagues (P50 AG11711) have designed a peer support intervention aimed at reducing social losses among dementia family caregivers by linking such caregivers with trained volunteers who have also been dementia caregivers. Support was provided for their hypothesis that the program would be most effective for persons whose social networks were deficient prior to the intervention. Caregivers with fewer support resources were much more likely report high participant satisfaction. Similarly the intervention only had positive effects on the psychological wellbeing of those participants who had weak social networks upon entering the program. This finding reiterates the importance of program targeting. Persons who are having problems in the area of social support obtain most benefit from a socially based peer support intervention. Program resources may be most efficiently used when they are made available to those persons in greatest need, rather than to all caregivers.

Future Program and Research Activities.

- This next year of the SCU initiative will be devoted to cross-site and meta-analyses. Building on findings emerging from the SCU Initiative, investigators have received additional funds for the translation of research into a WWW information site (<http://www.WRESCU-NAC.org>) that can be accessed by nursing home administrators and policy makers. Future research recommendations include going beyond the SCU/non-SCU dichotomy to test the effectiveness of different best care practices identified in the SCU initiative.
- These efforts are being complemented by two NIA studies examining the outcomes of residential care for persons with dementia using similar measures as those developed in the original SCU initiative.

- Using dementia care in general and the REACH interventions as a specific case example, program staff is planning a series of working group meetings to explore conceptual and methodological bases for psychosocial intervention approaches to health challenges. Investigators are adapting statistical optimization approaches derived from the engineering field to examine different intervention inputs and outputs.
- Two other promising research opportunities have been identified for future development: 1) the caregiver's role in clinical trials for AD drug management; and 2) the integration of caregiver and health services research questions into NIA Alzheimer's Disease Centers.
- While greater attention to research on the physiological consequences of caregiving stresses and burdens, and the role of mediating factors, is desirable, more intensified efforts in this area call for additional program staff expertise in psychoneuroimmunology.

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